

NEWSLETTER

Number 2



Photograph by Bliss

Welcome to the second Preterm Birth Programme newsletter. We want to keep you up-to-date on progress with this important area of research. We are delighted that you are reading about the programme and are grateful for your time if you are, or have been, involved.

The aim of this five year research programme is to improve the care given to very preterm babies (those born before 32 weeks gestation) and their families.

The work, which is funded by the National Institute for Health Research, began in 2011 and is now in its second year. Much of the preliminary work has been completed and early results from the research are encouraging.

We feel that we now understand more about what families of premature babies think and feel about the care they received during this difficult time. We have also identified some topics that both health professionals and parents think should be considered for future research.

We've gathered some useful information from the study that weighs babies at birth while their umbilical cord is still intact. This will help the research team to decide important details of the pilot cord clamping trial (e.g. the length of time before cutting the cord) that will begin to recruit mothers and babies in March 2013.

We have looked at how we can encourage parents to take part in this important research trial, and how best to approach them sensitively. In some centres the trial will involve the use of a new piece of equipment - a specially designed trolley - that enables doctors and nurses to care for the baby at the mother's bedside rather than at the side of the room away from the parents.

Delayed cord clamping trial

A very important part of the programme is to work out whether it would be possible to carry out a large trial involving lots of hospitals comparing deferred cord clamping and initial care at the bedside, with immediate clamping and initial care at the side of the room..

When a preterm infant is born, the cord is usually clamped straight away and the baby taken to a resuscitaire at the side of the room. This trial will look at the feasibility of a more family-centred approach to give initial care to the baby at the bedside, so the mother and her partner can share the first few moments of their baby's life, and to wait a short time before clamping the cord to allow blood flow to continue between the baby and the placenta.

Most of the results of the work explained in this newsletter will be used to design the pilot trial. Work is taking place to make sure that the proposed plan is approved by the NHS and can be conducted ethically.

There will be a minimum of eight hospitals in the UK taking part in the pilot trial. These

will have trained teams of clinical staff including an obstetrician and neonatologist who will be involved in the care of the mother and baby during the trial.

To make sure that we understand whether care at the bedside (with delayed cord clamping) is the best way to care for premature babies, we will put the babies we recruit into two different treatment groups: one group will receive their care at the bedside (with delayed cord clamping) and the other group will be treated in the usual way at the side of the room with immediate cord clamping. The babies from both groups will then be followed until their second birthday to assess whether the different approaches to treatment have made any difference to their progress.

We hope to begin recruiting to this trial in March 2013 in Nottingham. Hospitals in Bradford, Liverpool, Wolverhampton and Leicester will begin recruiting soon after.

For more information on the trial please contact Eleanor.Mitchell@nottingham.ac.uk

This research programme is being managed by a team based at the University of Nottingham.

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www.nottingham.ac.uk/pretermbirth

Or visit our facebook page at:

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This research is supported by Bliss the charity for babies who have been born too small, too soon, too sick and the National Childbirth Trust the UK's largest charity for parents.



What have we found out so far?

The Preterm Birth Programme has several elements to it that will help doctors and nurses improve the care given to very premature babies at birth. Results from some of the studies are beginning to emerge.

Parent's experiences

A very important part of this research programme is gathering parents' views about the care and treatment they and their babies received.

We interviewed parents to find out their experiences and satisfaction of care. Overall, they were very positive about the care they received, and felt that very little could be improved, which is a very encouraging finding, but where care can be improved we now have further information to communicate to caregivers. We also asked about parents very first experiences with their baby. Most reported seeing their baby at birth, if only briefly, but some parents said that they didn't see their baby until they went to the Neonatal Unit.

Interviews with parents revealed that the kind of things that matter most to parents and affect their experience of the birth of their baby. Issues that were particularly important were staff appearing calm and appearing confident during the birth. Mothers valued being listened to, and both they and their partners appreciated staff helping fathers to feel involved during the birth.

The results of this study have been used to develop a questionnaire that will be used in other elements of our research programme and will help us understand more about how best to care for preterm babies and their parents immediately after birth. We will have a detailed report of the study to share once it has been published.

A new trolley for the care of premature babies

We want to find ways that enable doctors and nurses to provide immediate care to babies right next to their mother. We think that it is important to give parents the chance to share the first few moments of their baby's life. We've designed a special trolley that means all the essential equipment doctors need when providing initial care to preterm babies can be brought right to the mother's bedside.



Photograph by Bill Yoxall

The trolley is called 'Lifestart' and is currently being tested in Liverpool Women's Hospital. It will then be used in some of the centres during the two year pilot trial that is going to look at whether it is better for the baby and the family if initial care is provided at the bedside compared with at the side of the room.

Measuring Placental Transfusion

This study has been measuring the amount of blood that flows from the placenta to the baby immediately after birth. Newborn infants are placed on special digital scales next to the mother's bedside for a set time. Doctors and nurses involved in this study received special training before recruitment of parents and babies began in March 2012. To begin with only term babies were weighed, but now the hospitals participating in this research are recruiting preterm infants. The information gathered by this study will help us understand how long it takes for blood from the placenta to flow to the baby. This will help with the planning of the pilot cord clamping trial, particularly how long to wait before cutting the cord. Thank you to all those parents who have taken part in this important study so far.



Skye Swinton 23/04/09 @ 27wks 1lb 15oz or 880g

Ruth Swinton from Cheltenham went into labour at 27weeks and gave birth to a daughter who weighed 1lb 15oz. Skye spent three weeks in Reading in the NICU as there was no cot space at the local hospital. Staff felt she was stable enough to be transferred back but they had to wait for a cot space. Ruth and husband John found this an extremely difficult and stressful period. They were staying in hotels while Ruth was trying to express breast milk for her. John was signed off work with stress.

Bliss (who are supporting this research programme) were very helpful to Ruth and her husband during this difficult time. Ruth says "Skye has since been diagnosed with mild cerebral palsy which has been difficult but the friends I have made through the Bliss messageboard have provided ongoing support."

Priority setting survey

We are working in partnership with the James Lind Alliance to bring parents and clinicians together to identify the most important areas where research is needed in the area of preterm birth. To do this we ran an on-line survey from March to September 2012 in which 1,050 people participated.

We are currently looking at the results of the survey and topics that have been suggested as important include 'genetic issues of preterm birth', 'developmental concerns of infants at school age', staffing levels on units, and communication between families and health professionals. These suggestions will be prioritised and recommended as future research topics.

